USER RESEARCH INTERVIEWS

INTERVIEW PARTICIPANT 1 | ERIC PETRIE, MD, MS

Dr Petrie was our SME and has the following credentials:
Associate Professor Psychiatry & Behavioral Sciences,
and Adjunct Associate Professor Radiology,
University of Washington
Senior Investigator, Mental Illness Research, Education, and Clinical Center (MIRECC)

DOCTOR QUESTIONS

- 1. Can you tell us about the diagnosis and progression of Alzheimer's?
- 2. How regularly do you meet with patients?
- 3. What methods have you used when managing medication for patients?
- 4. what were the most successful?
- 5. least successful?
- 6. What are the greatest hurdles patients face with medication adherence?
- 7. What factors contribute to increased adherence rates?
- 8. How many medications are typically prescribed for Alzheimer's and TBI patients?
- 9. What are they?
- 10. How frequently are they taken?
- 11. Are there any special requirements? (e.g. a pill that must be taken with food)
- 12. Do you think that patients would benefit from a new tool for medication management?
- 13. Are there any features that you would want to see included in a design?
- 14. We realize that we are working in a sensitive design space. Do you have any recommendations for how we can help patients and caregivers feel comfortable interacting with our product or participating in our study?
- 15. Is there anything else that you would like to share today?

DOCTOR NOTES

Interviewer: Gail

Notetaker: Long

Can you tell us about the diagnosis and progression of Alzheimer's?

Diagnosis

So 100% accuracy of Alzheimers would be to conduct an autopsy- look at brain, slice, stain with abnormal protein deposit

- Usually alzheimer's disease is a probable find but it is not for sure
- Alzheimer pathology can have similar signs of micro cerebral pathology
- No accurate measure to determine alzheimer's until person is dead
- Dementia category branching from vascular, alzheimer, strokes in brain, related to parkinson's disease, other general medical conditions

Dementia is an umbrella term

Characteristics

- Cognitive disabilities
- Short term memory loss
- Difficulty with language
- Difficulty in understanding spatial recognition (praxias) i.e. eating utensils
- Difficulty in performing simple tasks such as cutting, putting arm in hole of shirt, awareness of area
- Getting lost
- Finding orientation in space

Unable to perform Executive Functions

 Ability to plan, execute multi behaviors examples such as cooking thanksgiving dinner which involves multi tasking

Judgment and impulse control

• He gives an example of a woman who was opening a can of soup but didn't cooking it. The woman did not understand the concept of reheating

Progression

- Between the onset and end form of the disease is roughly 8-9 years
- Short term memory gets worse as time passes

- They will end up needing more help executing basic tasks such as bathing and dressing
- They lose problem solving ability
- Lose ability to practice simple tasks such as understanding what soap does
- Alzheimers may cause the patient to be Bed ridden which promotes death
- And then can develop pneumonia
- By being bed ridden, the patient may not walk which risk more of developing diseases, blood clots, which may lead to strokes
- It is a spiraling down effect whereas people die from other illnesses
- Some people have faster progression such as people from ages of 50 which is linked to genetic defect
- However, small fraction of population are genetically linked to the disease
- Large number of people as so far we know would be sporadic
 - Presenilin mutation in families
 - Usually less than half percent of the population

Caregiving

- Depends on patient and caregiver as well as social situation
- Some people have caregivers that are highly skilled which can manage the person who is becoming less functional
- Loss of day/night cycle = wandering
 - Patients can wander in and out of the house, which causes stress on caregivers
- Q: is there family member that has time?
- If you have money to pay for caregiver it would be great
- It would be difficult if you didn't have money to live from day to day
- Those who don't have money usually visits nurse services Places usually limit to basic care needs groom, toiletry, skilled nursing
- If theres local place for day center can be great help for caregiver to drop off because its emotionally taxing on them. Sometimes caregivers need timeout to regroup
- Usually become institutionalized when family can no longer take care

What methods have you used when managing medication for patients?

Depends on how compliant people are Just getting diagnosed doesn't mean you have to be bed ridden or institutionalized There can be a long stretches in between stages

- Organizing meds early on can be simple as having medi-set pill box
 - Multiple divisions promotes good organization
 - Person who would remember on tuesday have day pills which helps people stay organized
 - Medi sets can make huge difference in managing medication
 - If you have to take more than once a day, compliance diminishes *
- Patients who can't remember
 - Caregiver who may call its time to remind them of which pill to take
 - Hospital puts information on whiteboard
 - such as "It is 2015, take medicine at noon" with clock nearby
 - If people cannot read analog clock it would be digital clock because of spatial recognitions

What were the most successful?

• Medi sets but patient might not have consistent short term memory to be able to remember

Least successful?

- Hard to cue patients to remember
- Can use alarm clock but can people remember?
- Digital readouts are easier for those with dementia than analog clocks

How is adherence tracked?

- Trials
 - give patient medi set
 - o check pill use upon return
- Blood tests
 - don't work for alzheimer's meds

What are the greatest hurdles patients face with medication adherence?

- "Remember to remember part"
- Not having a stream of resources available
- Degree that caregiver can help

What factors contribute to increased adherence rates?

- Can you stream together other people to help? People come in at certain times
- Create social bonds to help manage
 - Hiring people to administer meds
 - Mild cognitive impairment
 - Not reached at alzheimer's just yet
 - Not impaired of taking care of self
 - 10-15% vascular which may stay at base line?

How many medications are typically prescribed for Alzheimer's and TBI patients?

- People who have symptoms but not alzheimer's
 - Neurons that release chemicals
 - Cholinesterase inhibitors
 - Some may do better with one than the other
 - May contribute to nausea
 - May induce bad dreams during sleep
 - should be taken during the day
 - 5mg once a day
 - Memantine
 - prolong self care activities
 - once a day medication
 - Medication won't actually bring people back to old state of mind
 - Can only slow the progression
 - Age is biggest risk factor
 - Other medical conditions may cause proximate cause of death
 - Can help keep people out of nursing home
 - Save money
 - Not paid for by Medicare does not cover long term treatment

How frequently are they taken?

- Depends on medication
- Cognitive medicine
 - Ariselp? 5-10 milligrams per day
 - o Meminteen acts on certain transmitter glutamate
 - Data is good from mid-late stages, won't bring back to where they were but effect would be prolonging the activity of taking care of self
 - One a day med
- 12:29 (when I had to adjust camera, require to watch video again)

•

- Non medication*
- Frontal lobe inhibits behavior
- Alzheimer's
 - Loses ability to control emotions
 - "This is not my home"
 - Lack of recognition
 - Faces
 - Environment
 - Patient lacks verbal skills to explain agitation
 - Pain
 - Constipation
 - Urinary tract infection
- Severe constipation can be extremely uncomfortable
- Irritably to aggression
- If healthy patient would use 1-2 pills
- Depending on other illnesses people can have complex regimens
- If we can't control themselves of aggression, give anti-psychotic medicine as a calming effect
 - Increases death of cardiac arrest
- Anti-depression meds help with aggression
 - Personality disorders
 - o TBI
- Possibility of drug interaction can be a concern if meeting with multiple physicians
- Examples such as of person who had duplicated medicine
 - Happens more often than people admits

Do you think that patients would benefit from a new tool for medication management?

- "I think so, I don't have a conceptual of my own of what that might be"
- "might be different things for different people"
- Depending on how demented people are

What other ways can we cue them?

- Verbal reminder?
- Digital cue reminder?

Are there any features that you would want to see included in a design?

A Device system that can log data

- To connect to different places and diff doctors
- Reduces duplicated medicine
- Consider patient privacy, always a concern with wearable devices
- Help with pill recognition
 - o generics all look alike
- Current record systems don't "talk" to each other
 - o individual deviced identify red flags bad pill interactions
- Security of pill containers

We realize that we are working in a sensitive design space. Do you have any recommendations for how we can help patients and caregivers feel comfortable interacting with our product or participating in our study?

- Huge question to think about
- Hard to separate life from fantasy

Is there anything else that you would like to share today?

- How can we make it easier on the caregiver so that their quality of life is not destroyed
 - May burn out when circadian rhythm is disrupted
 - Making house secure enough to sleep
 - Consider how clever each individual with dementia are

- As people get older sensory input gets degraded
 - Can't hear , can't see, which sets up for paranoia
- Problems with balance
- Home security
- Keep caregivers from getting burned out
 - o Consider caregiver as end-user
- Confusion of spatial recognition "Sundowning"
- Can they stay at home? Or have to institutionalized
 - If Alzheimer can delay treatment by 6 months, how many millions of people would die first from other diseases

Jessie Fann

- Head injury program
- Doing a lot of telephone based management with moderate to severe injury
- Why did you develop this?
 - Output Properties of the control of the control
 - Do other people such as caregiver become involved?
 - People call and ask how to manage things

Linda Terry (Alzheimer research center)

- Psychosocial aspects
- Caregiver focus
- Alzheimer's disease research center

INTERVIEW PARTICIPANT 2 | BOB FISCHER

Bob was our Traumatic Brain Injury patient

PATIENT QUESTIONS

- 1. Can you tell us about your medical history with Traumatic Brain Injury?
- 2. Has the diagnosis had any effect on how you manage your medications?
- 3. How many medications do you currently take?
- 4. how frequently are they taken?
- 5. Are there any special requirements? (e.g. a pill that must be taken with food)
- 6. What methods or tools do you use to help you manage your medications?
- 7. Do you always take your medications in the way your doctor prescribed them?
 - a. have you ever forgotten to take a dose?
 - b. have you ever forgotten if you already took a dose?
 - c. have you ever misdosed?
- 8. How often do you interact with a doctor or other medical professional?
- 9. What are the greatest hurdles that people face with medication adherence?
- 10. What factors contribute to increased adherence rates?
- 11. Do you think that people would benefit from a new tool for medication management?
- 12. Are there any features that you would want to see included in a design for a medication management system?
- 13. Is there anything else that you would like to share today?

PATIENT NOTES

Interviewer: Long

Notetaker: Megan

Can you tell us about your medical history with Traumatic Brain Injury?

Medical history

- 2009
 - Fell off stairs on front porch
 - Fractured skull
 - Bruised brain in front (Hepatic Encyphology)
 - Golf ball sized bleed (like a stroke)
 - 4 days in hospital
 - Sleep trouble
 - o Bright lights problematic
 - Noises
 - Couldn't recognize that he was not at full brain capacity
 - Not allowed to drive for months
 - Test to certify driving ability
 - Unaware of how much brain injury set him back

• 2010 August

- Wife out of town
- didn't remember going to bed
- Hadn't written about day in journal
- Drove in that state
- Forgot skills for an electrical project
- "I think i'm getting a cold or something"
- Wife took him to the ER upon return
- Liver failure had been triggering seizures
- 10 days in hospital
- Brain not working because liver not working
- Confusion about time
- Discrete events seemed to be happening simultaneously
- No sense of sequence
- No consciousness that live existed outside the hospital room
- Memories came back suddenly
- Has 2 autoimmune liver diseases

What methods or tools do you use to help you manage your medications?

Medication management

- Examines each pill bottle label every time
 - o "It was all my concentration to figure that stuff out"
 - o Still on anti seizure, liver meds and lactulose
 - 4 times a day
 - Tasted bad
 - "Very scary period"
 - o Numerous doctors and appointments
 - Lots to learn
 - o Not all pharmacies have all medications
 - Liquid medication
- Medi-set
 - See photos



Bob's pills left on tablecloth adjacent to computer as reminder



Bob's Medi-set



Bob's medi-set and tub he uses to store and organize pill bottles

Notebook

- Doctor
- Speciality
- Medication
- What medication does & which pharmacy they are at
- "End up with stacks of paper"
- "I had no ability to figure that out"
- Helped me feel "calmer"
- Mostly used by my mom (caregiver)
- Stayed on dining room table

Phone

- Started with flip phone, but wasn't sophisticated enough
- Got smartphone
- Would turn alarm off, and then forget that alarm happened and what it was for
- Alarm has to be persistent

Habit forming

- Take out pill empties and place by computer
- Keep box by computer
 - Stuff drops off the radar without a cue
 - Misses a set of pills once a month
 - Meshes pills
- "It's a big deal when one of my visual cues gets moved"
- o Bin
 - For non water pills
 - Gets very full
- Tray table
 - All the pills arrayed
- Keeping track of refills is difficult
- Has nightly personal routine and sets pills out for next day

Do you always take your medications in the way your doctor prescribed them?

- have you ever forgotten to take a dose?
- have you ever forgotten if you already took a dose?
- have you ever misdosed?

Pills

- One pill must be taken 15 minutes before eating
- "I don't manage to do that very well"
- "My que is my heart burn"

How often do you interact with a doctor or other medical professional?

Doctors

- Haven't seen neurobiologist for several years
- Sees a general practitioner/ liver doctor
 - He explains things clearly
 - "that was key"
 - Every 2-3 months
- Always accompanied to appointments (forgets things)

Does your medication change much now?

- 8 medications currently
- Medication regimen is constantly changing
- Ulcerative colitis medication
- Sublingual medication (under tongue)
- Categorizes medication by ailment -> Brain, Gut
- Shows us the box he uses for separating his medication

What are the greatest hurdles that people face with medication adherence?

Challenges of adherence

- filling up the pill box distracts me from taking my morning dose
- regimen still evolving
- "when you complain to your doctor, they give you drugs"
- 6-7 medications
- feels the need to self test symptom treating drugs
 - o colon removal solved some medication overlap
- keeping track of refills difficult

Are there any features that you would want to see included in a design for a medication management system?

Design requirements

- accommodate pills 4 times a day
 - o taken with water
 - taken before eating
 - taken sublingually
- make the right pill colors visible
- customizable
 - o pills sorted for "gut" and "head"
 - labels that don't rub off
 - number of boxes
- portable
 - o packs in suitcase easily
- not obtrusive
- Fix: boxes popping open and spilling pills
 - o difficult to pry up containers
- generally only need to access one pill box section at a time
- would be nice to pop one out and back in
- more natural backup set of pills

INTERVIEW 3 | KEN & DOROTHY THYNES

Ken and Dorothy were our Alzheimer's patient and caregiver team.

PATIENT & CAREGIVER QUESTIONS

Questions for Caregiver/ Patient interviews

- 1. How long have you been managing _____(Alzheimer's or TBI)?
- 2. Has the diagnosis had any effect on how you manage your medications?
- 3. How many medications do you currently take?
 - a. how frequently are they taken?
 - b. Are there any special requirements? (e.g. a pill that must be taken with food)
- 4. What methods or tools do you use to help you manage your medications?
- 5. Do you always take your medications in the way your doctor prescribed them?
 - a. have you ever forgotten to take a dose?
 - b. have you ever forgotten if you already took a dose?
 - c. have you ever misdosed?
- 6. How often do you interact with a doctor or other medical professional?
- 7. What are the greatest hurdles that people face with medication adherence?
- 8. What factors contribute to increased adherence rates?
- 9. Do you think that people would benefit from a new tool for medication management?
- 10. Are there any features that you would want to see included in a design for a medication management system?
- 11. Is there anything else that you would like to share today?

PATIENT & CAREGIVER NOTES

Interviewer: Megan

Notetaker: Stephanie

How long have you been managing Alzheimer's?

Ken: Dorothy has had dementia 2-3 years

• Medication is emlatipene (?) and one other that they cannot remember

How many medications do you currently take?

- Ken takes 9 a day
- She takes 3 medications
 - One is a baby aspirin morning
 - Levistatin pill, morning and evening
 - Emilatapene morning
 - Blood pressure medicine
 - Excellon a patch he puts on her every night for medicine, size of quarter, pain in the butt because it's tough to put on. Toxic. Put the patch on her back. Can't put in the same spot for 2 weeks. Don't take patch off until you put the new one on, and that works well

How frequently are these medications taken?

Frequently

- Takes medicine only in the morning
- Ken administers the medicine
- Had a problem because Ken thought she took medicine yesterday already, but the pills were still in the tray. Doesn't forget anymore since then

What are some methods or tools you use to help manage your medication?

How you keep track

- Refill process
 - Marked on the prescription bottle
 - Can have once a month or for longer periods (2-3 months) but we continue to use the shorter ones
- All other medicines are pill based

Have you ever forgotten to take a dose?

Mistaken dose

- Don't have issues with taking again once already taken
- About 4 times forgot to take
- Like pill box system because Ken can check if it was missed
- Paper stating that Ken will give her medicine
- Didn't want to double up, so if they couldn't remember they wouldn't take it because they wouldn't want to accidentally double up

What changes would you like to see made to the pill box?

Changing about pill box?

- Ken: The one he has had a trigger on it to keep from flipping open and spilling pills, and he likes that. But Dorothy's is more old fashion, so he puts tape around it to keep it from spilling
- Both agree that Ken's works fine
- Ken wants to get one of his for her
- Hard to open towards the end?
 - o It is difficult, and have done it. But don't want to destroy the system
 - Hard at the beginning, but you get used to it
- Use two pill boxes for Dorothy because Lovastatin is twice a day
- Ken fills pill box Friday, same day at the same time
- Larger pill box
 - Ken feels the larger pill box seems complicated

How often do you interact with a doctor or medical professional?

How often see doctor

- Dorothy sees doctor every other month
- Ken every month
 - Check Ken's blood because of the diabetes and blood pressure

How often does your medicine change?

How often do meds change

- Ken
 - Minor changes
 - Size of tablet or pill, same strength but different manufacturer
 - Doesn't want two pills of the same color
 - If they change it and don't tell him, he gets back to them and makes sure they're right
 - Shape, size, and color, all important and he pays attention

What are your greatest hurdles concerning medication adherence?

Medication adherence

- Dosages are controlled by the doctor
- Time
 - My responsibility
 - Don't vary more than 30 minutes
 - o D: "It's part of the way we live now."

Increase of Adherence

- Big horse pill is the hardest part
 - Dry pill doesn't slip down like a capsule
 - o Drinks milk to help
- Dorothy doesn't have as many problems

Do you think that people would benefit from a new tool for medication management?

Benefit from new tool

- K: Absolutely
- D: Yeah, I think I would too
- Both: Think they're always good for improvement
- K: Excellon can be improved (the patch) is for memory \$90/ month
 - Applies it when she's already in bed
 - Scrubs hands with hot water (as hot as he can stand)
 - Had problems with gloves because it doesn't fit his hand well
 - Put old one in empty envelope and roll it up tight
 - Wash hands again and scrub very well again
- Rotation of patch
 - 4 rows in a month
 - Zig zags up, over, down, over, up again, etc.
 - Works very well
- Changes
 - D: Have to play with everything, different things work for different people
 - Open it like a band-aid
 - Just a small extension on top or bottom of the plastic would help, like a tab

Before Ken took over medicine, could anything have helped remind Dorothy?

- D: I think we tried everything
- It's impregnated in Ken now, he checks really closely
- Was getting worried because she would say she remembered taking it, but boxes wouldn't lie

Design Questions

Thoughts on watch design

- Incessant beeping bad
- Every 5 minutes or so, Dorothy says maybe

Habits are formed, no physical checklist

 Never forgot to call in refill -- BUT WAIT today he sent in Dorothy to pick up the wrong one was picked up Ken likes that he can order them off the phone, thinks it's the best system

Doesn't take any time at all

Automated refill process

- K: Not uncomfortable. They have that. But they send you. And they send other things you don't need. Like doing it myself because then I know what I'm getting and she's getting. If you rely on someone else and they screw it up...
- Like to be in control of your own medicine
- Complications with filling yourself
 - Have to give extra time because the weekend makes it so you take longer

Other design ideas

- Like this because it's A dose (one dose)
 - The large pill system was larger
- Push button on the end is designed to be difficult

Stressful to manage medication for both?

- No, absolutely not
- Feel so much better now that there's a system, but now you can look and find out
- Keeps Dorothy's medication in another bathroom behind something she doesn't like to make sure she doesn't get to it



Dorothy's pill containers for morning and evening



Dorothy's pill containers showing label system



Ken's pill container with locking feature



Ken's pill container with locking feature - shown open



Ken's pill container with locking feature - showing the "lock"



Dorothy's patch medicine packaged

INTERVIEW PARTICIPANT 4 | GWEN FISCHER

Gwen Fischer was the primary caregiver and mother of our TBI patient, Bob.

CAREGIVER QUESTIONS

Questions for Caregiver/ Patient interviews

- 1. How long have you been managing _____(Alzheimer's or TBI)?
- 2. Has the diagnosis had any effect on how you manage your medications?
- 3. How many medications do you currently take?
 - a. how frequently are they taken?
 - b. Are there any special requirements? (e.g. a pill that must be taken with food)
- 4. What methods or tools do you use to help you manage your medications?
- 5. Do you always take your medications in the way your doctor prescribed them?
 - a. have you ever forgotten to take a dose?
 - b. have you ever forgotten if you already took a dose?
 - c. have you ever misdosed?
- 6. How often do you interact with a doctor or other medical professional?
- 7. What are the greatest hurdles that people face with medication adherence?
- 8. What factors contribute to increased adherence rates?
- 9. Do you think that people would benefit from a new tool for medication management?
- 10. Are there any features that you would want to see included in a design for a medication management system?
- 11. Is there anything else that you would like to share today?

CAREGIVER NOTES

Interviewer: Stephanie

Notetaker: Gail

Can you tell us about your experience caring for Bob after his accident?

Caregiver mindset

- Experience of shock that this is happening to you. You don't expect this to happen to you, what the prognosis,
- You don't know the issues, these were the things that contributes to her state of mind.
- This is someone you love.
- Bob was mostly sleeping or groggy when he was awake.
- Janet and her were in a state of shock and unsure about how bad or long this would be. Any crutch or assistance that they had access to was wanted.

How long were you there?

- Got an immediate seat and arrived within a few days of the accident. They had resources to get a ticket.
- But she considered the financial impact for those without the financial resources.
- It was decided with husband, that the priority to get one of them out to help.
- They had pets at home to take care of, so the husband stayed.
- Things to consider are pets and jobs of caregiver.

How did you help organize the medications for Bob?

- Unclear paper and pencil.
- It would have been important, but his overall state was more important.
- He needed sleep and if he slept was he going to wake up.
- Medication was one more thing to do, and making sure he was eating.
- The general concern for daily living.
- Activities is paramount.
- As a teacher, I rely heavily on paper and pencil.

- If your mind is burdened, it helps to relieve the burden to write things down.
- When her father was hospitalized, she had to fly to Atlanta to help.
- One of things she did was buy a spiral notebook.
- When she thought of something that needed to be done she would write it down to clear her thoughts.
- It's an easy solution.
- You don't want to have to learn to do something when you have all these other things going on.
- She was advocating low tech and talked about tech adoption in older people.
- Ease of use, easy to enter information and accessing it.

Would a system be helpful? Or would pen and paper be best?

- You have to keep in mind that user vary.
- Some may be tech savvy and some that aren't and design for all of them.
- That's the real challenge facing us probably these days

What key pieces of information were you recording?

- Appointments
- Doctor names and phone numbers
- Special foods
- Times of activity eating, sleeping
- Shopping lists
- Medicines and other equipment that was needed (like a walker)
- Things you're supposed to tell the doctor at your next appointment but isn't urgent
- Instructions from doctor
- The person accessing this information might need a calendar view or chronological view. You're living very much day to day.
- It's difficult to determine urgent and can be done later.

What was the notebook you created a notebook like?

- Interesting that she doesn't remember using the notebook.
- William James definition of memory is to forget useful things.

Do you use notebooks in your everyday life?

- Good brain exercise to not rely too much on memory. But much sloppier in daily life than when in a crisis or stressful situation like we are talking about.
- Context of event is important.
- Alternates between computer and paper and pencil.
- Mini Ipad but mostly user for reading
- Uses Word on computer for most writing or InDesign for flyers.
- She's fighting fracking and sending out information on meetings
- Awareness of audience, sometimes has to get in touch with people the old fashion way. Some people don't even have computers.

Can you tell us about Bob's medication regimen?

How many pills?

- She doesn't remember details.
 - This one is no milk with, one an hour before a meals.
 - This one every 3 hours.
 - Or drink lots of water with it.
- The timing and the circumstances for each medication is difficult.
- Documenting any changes, fever, side effects, when to notify doctor.
- And going back to the state of mind of caregivers, because the situation with the brain. This could affect the person's life permanently, the state of mind requires a lot of help.
- She remembers really glad that Janet was there too for support.
- Community relieves stress to talk about it, sounding board, and for external reminders.
- Experimenting with different types and strategies to remember.
 - If it's too hard, it won't get used.
 - The simplest is the one that will be used.
 - The medicine is what is supposed to make things better.
 - o If you screw it up, it's a double problem.

Are there any ways that you change the doctor directions to better suit your needs?

• If there are instructions like you must be upright, and someone goes and lies back down, you need to consider how to design for that or instruct patients not to do that.

Was there ever a time where they forgot or didn't give it as prescribed?

- Doesn't remember, but it's common that something interferes.
- Had questions about missing doses
 - Should I take it an hour later?
 - Should I call the pharmacist?
 - Should I just skip this one and take the next scheduled dose.
 - Asked other caregiver (wife) How would you have handled that?
 - Depends on how much information you have about the medication.
 - Were there no special instructions, it's not a special medication that's urgent.
 - Or look it up online nowadays.
 - Even ask a family member about what to do.

How often would you interact with the doctor?

- I don't remember.
- At least once or twice when we called the doctor.
- He had a couple of doctors he was dealing with and she met both of them.
- But does not remember how many times. No specifics.
- It's important for doctors to know something about the family and the patient to remind them they are treating a person and not a condition.
 - She tells them something about herself to the doctor so that they can make an association to her that's not medically related.

Personal experience with managing medications adherence? Hurdles?

- Eliminate or reduce anything else going on, distractions.
 - Children in the household
 - o other tasks that need to happen
 - changes in the patient's condition

- If they aren't tolerating the medication, or is the patient sleeping or let them sleeping.
 - Which is better the sleep or the medication and other priority issues like that.
 - The patient's unwillingness to take medication.
 - Trouble swallowing
 - Prioritize
 - Patients physical condition
 - Patient's mental state
 - All the medication restrictions and directions
- Everything feels urgent when you're starting out on this stuff after an accident. You know a little more in-person about the patient's condition.
- I remember Janet calling and feeling really panicky, you're filtering this information and you don't really know what's going on or what's going to happen.
- More than one caregiver helps.

Did you discover any strategies that helped him?

- Easy access to as much information as possible.
- Our family doctor has begun using an online medical records system.
- In some cases when the doctor posts something, there's a new icon that tells you more about the medication.
- Blood test results, and you don't know what they mean, but you can click a button that explains your results and where they fall on a spectrum of results.
- Some people want to know if I should do it or not do it, and don't want all the other information.

Do you think people would benefit from a new tool?

- I think so, it sounds useful to me.
- My only hesitation is how easy would it be to use. If it's an urgent situation I find discovery of a new tool or trying to complete a task.
- The decisions involved are anxiety or life or death or permanent damage because you made the wrong decision, these are things to consider the level of information available
- High-tech or low-tech solution might be best.
- Simple information and interface is important

Are there any features that you would want to see included in a design for a medication management system?

- Would like to ability to email a doctor
 - It's not life or death, but you don't want to wait for an appointment in two weeks
 - It's difficult to get the answer on your own.
 - Instead of a call, you could get an email within 24-48 hours that would answer your question would be really helpful.
- Availability of levels of information to a variety of users.
 - From basic to more technical information would be helpful.
 - How do you sort out what's useful.
 - Layering the information.
 - Basic decision making, take it late or not.
 - You should talk to your doctor if you miss this.